Caring for Washington Individuals with Autism Spectrum Disorders Task Force

Emerging Themes of Concern
November – May 2006

The task force identified numerous ways to improve the system of care. Only some of these ideas are being proposed currently, but this document will provide a convenient way to maintain this information for future use by task force members and the public.

Early Screening, Diagnosis, and Referral to Intervention

1. All children will be screened for autism before the age of three (goal: 18 months) -

2. All providers in child find positions will be knowledgeable in timely identification of children at risk for an ASD diagnosis.

3. All children identified at risk for an ASD diagnosis will be immediately referred for further evaluation and intervention services (simultaneously).

4. All children identified, diagnosed, and/or referred will be monitored for follow-up.

5. Process for identification and (referral for) diagnosis and intervention services in the early intervention and public education systems will reflect best practice guidelines (see "Educating Children with Autism" from the National Research Council). Implementation will be consistent across schools and across districts.

6. Process for identification, diagnosis, and referral in the healthcare system will reflect best practice guidelines (see Autism Alarm, First Signs and AAP's recently revised guidelines).

7. Statewide database will be developed for assessing prevalence and incidence of ASD.

8. Data regarding treatment, interventions, and outcomes will be collected for assessing effectiveness and possible profiling (strive to answer "what works and for whom").

9. Local, regularly occurring trainings in Identification, Diagnosis and Referral for ASD will be available to healthcare providers and all those in child find positions/occupations (recommend First Signs, CME approved training). MCHAT screening tool

10. Resources and tools for Identification, Diagnosis and Referral will be made available to primary care providers (including appropriate areas in hospitals and clinics) and all those in child find positions (day cares, ancillary service providers, education system, ITN, DDD, etc….).

11. A plan for improving public awareness will be adopted and implemented (suggest collaboration with CDC's public awareness campaign: Learn the Signs Act Early).

12. Ask what would promote improvements in health? The outcome we are looking for is that no disparity will exist. We have much work to do around multi cultural medicine. A plan sensitive to such issues as ethnic diversity, rural location, and foster care status (and any other issues impacting standard accessibility) in providing the above to all children to be developed and implemented.

13. Training in the importance and method of early identification, diagnosis, and referral will be made available through courses for related services in higher education (special ed, general ed, ancillary services, psychology, etc…) and medical residency (family practice, pediatrics, psychiatry, etc…) programs.

14. Systematic plan for evaluating short and long-term effectiveness of items implemented (ie, did timely identification and diagnosis improve? Are families satisfied with system of referral? Are providers reporting knowledge of screening tools and local resources? Will require baseline data, and ongoing data collection.

Evidence-based practices

Appropriately trained personnel

Regional centers will have available appropriate training for individuals, families and professionals

Consistent process throughout the state to determine appropriate educational programs for each individual

High vs low functioning kids – issue of discriminating against high functioning individuals with ASD.

Expand intervention from pediatrics to all providers

1. Good evidence-based standards for effective services with necessary resources for interventions and weaving intervention services into the lives of individuals of all ages who experience autism;
    a. Birth to 3
    b. Ages 4-5
    c. K-Middle School
    d. Middle School to Adult Life
    e. Adult Services
    f. Family/Community life

2. Evidence-based standards for effective services should include;
    a. An array of strategies; which may include 25 hours per week for early intervention services, 1 one 1 instructions, etc.
    b. Emphasize cultural competency
    c. Be sensitive to the different ways that people with Autism Spectrum Disorders learn.
    d. General Education and Special Education Teachers partnering together

3. Resources and continued development of state, regional, local, district and specialists trained on good Autism research based standards for whole life services and supports;
    a. Medical/Dental/Mental Health
    b. Family Support/Respite
    c. Personal Care
    d. Education
    e. Post Secondary Education
    f. Assisted Living/Residential
    g. Employment/Supported Employment/Vocational

4. Trained staff to provide- evidence- based services;

    "People who work with children with ASD need to have a minimum of xxx (list)"
    a. Medical/Dental/Mental Health
    b. Family Support/Respite
    c. Personal Care
    d. Education
    e. Post Secondary Education
    f. Assisted Living/Residential
    g. Employment/Supported Employment/Vocational

5. Autism Spectrum Disorder expertise present at regional, local and district levels for timely referrals to multiple programs and services without waiting lists through the continuation of our statewide autism leadership (AOP) and development of local training programs (similar to ESD112 Regional Autism Consulting Cadre, University of Washington Autism Center, Seattle and Tacoma, Northwest Autism Center, DOH-CSHCN).

6. Recommendations from the Autism Task Force should sustain efforts that already exist in the State of Washington and aim to help all kids with disabilities, without overwhelming schools and taking resources away from other groups of students.

Evidence Based Trustworthy Information

Recommendations should be tied to evidence based approaches.

By law, school districts and insurance companies are required to provide services that are evidence based**.** We have to use evidence based recommendations in the report.

Washington has a new law regarding evidence-based decisions for Medicaid coverage

Evidence based information should be made accessible to the public and provide the basis for statewide programs. This information should be made available through the Autism Outreach Project and the Statewide training program.

1. Articulate to the public what is known and not known about autism.
2. Enhance established resources (AOP, Autism Center, PDA, Medical Home) to provide information on early detection, treatment, and research findings to the public and to health care professionals
3. Disseminate evidence based information through statewide training program.

Training

Statewide training system based on evidence-based practices with regional and local follow-up and consultation

Must address multiplicity of audiences that interact with and support people with ASD

Training outreach to rural ethnic and culturally diverse populations

Recommend creating pilot programs where intervention strategies could be piloted, while gathering data and determining if the data could be generalized.

The prevalence rate of Autism is currently 1 in 166 individuals, placing an increasing demand on services in the private, public and educational sectors. Currently this demand is outpacing available services, and a dearth of educational and community based services exists. The ATF recommends the development of a statewide training program to increase provider capacity and provide regionally relevant technical assistance and training.

1. Implement *state-wide professional training* program, leveraging financial and technical resources already existing in UW Autism Center, Autism Outreach Project , Autism Cadre, and UW Professional Development in University of Washington Autism Center.
    a. Create statewide web-based resources through the University of Washington to provide information on early detection, treatment, and research findings to the public and to health care professionals
    b. Create and disseminate PDFs, informational videos, brochures, and newsletters to provide up-to-date information to parents and professionals
    c. Implement distance learning program to train educators and other professionals.
    d. Offer state-wide workshops and in-service training to birth-to-three centers, schools, community agencies, and mental health settings, focusing on the needs of individuals with autism from infancy through adulthood
    e. Provide training to primary care providers in early detection and treatment
    f. Regional Autism Facilitator trainers
    g. Provide ongoing technical assistance and training through regional Autism CentersUtilize UW technology resources, including:
        i. Web-based distance learning
        ii. Telemedicine capability
        iii. K-20 interactive telecommunications network

2. Enable colleges and universities to develop curriculum for students preparing to practice in professional and educational fields providing services to individuals with autism and their families.
3. Adopt an incentive program to retain and attract a broad spectrum of students preparing to serve individuals with autism in educational and professional disciplines. The incentive program may include but not be limited to loan forgiveness, tax credits, tax deductions and such other appropriate measures as determined by the Ohio General Assembly.
4. Establish standards for teachers working with individuals with Autism, with possible credentialing
5. Assess regional educational and provider needs
6. Establish regional Autism Centers to provide training to increase local capacity and technical assistance. Each center should provide regional training, direct service and technical assistance. Consideration should be given to:
    a. Population base
    b. Geographic location
    c. Existing resources (people, space)
    d. Proximity to state universities (e.g., WSU, UW)

Public School Education / Placement / Consistency

Partner with Early Learning Agency

1. Consistency
   a. consistent process throughout the state to determine appropriate educational programs for each individual
2. Funding for services
   a. all children for whom autism is suspected will receive a minimum of 25 hours per week of appropriate services (note—identify funding source)
3. Transition
   a. lifelong
4. Inclusion
   a. lifelong

Regarding regional trainings: There is a lot of interest in the Professional Development in Autism approach.

Need to encourage school districts to step up to the challenge.

IDENTIFICATION

1. Process for identification, referral for diagnosis, and provision of intervention services in the public education system will reflect best practice guidelines as outlined in "Educating Children with Autism" from the National Research Council. Implementation will be consistent across schools and across districts.

2. Guidelines will be developed and implemented to facilitate timely educational identification of students with autism, including defining a school-based professional training process on characteristics of autism spectrum disorders and outlining a school-based ASD screening process. Teams of staff members will be trained to provide a strong internal school resource. Members of "child find" teams will be trained to identify the "red flags of autism spectrum disorders."

3. Children identified at risk for an ASD diagnosis will be immediately referred for further evaluation and entry into intervention programs as soon as an autism spectrum diagnosis is seriously considered.

4. Process for identification and referral for diagnosis of autism spectrum disorders will include a formal multidisciplinary evaluation of social behavior; language and nonverbal communication; adaptive behavior; motor skills; atypical behaviors; and cognitive status by a team of professionals experienced with autism spectrum disorders. Implementation will be consistent across schools and districts.

FAMILY INVOLVEMENT

5. Families will be provided with materials and information specific to autism and educational approaches at the beginning of the assessment process. Parents will be directly involved and included as participating partners in development of the Individualized Education Plan (IEP). Parents will be included in assessment of outcomes in order to provide consistency and continued progress across environments.

EDUCATION

6. Education of children birth through age 8 will reflect best practice guidelines as determined by the National Research Council in "Educating Children with Autism". Recommendations for programming will be based on the child's individual needs which may include a minimum 25 hours/week, year-round instruction provision and components of direct instruction and inclusion with typically developing classmates.

7. Educational programs for all children with autism spectrum disorders will include family involvement; comprehensive assessment of skills and deficits; plan development; clearly defined goals and objectives; effective teaching strategies; assessment of the intervention; structuring the environment; applying functional behavior assessment to problem behavior; transition; opportunities with peers; and comprehensive team approaches.

8. Intervention programs for students with ASD will include systematic instruction, functional objectives and meaningful activities, functional communication systems, effective motivational systems, and a system for behavior intervention.

9. School Districts will implement deliberate plan for improving inclusion at all grade levels, including opportunities for interaction with typically developing peers in both unstructured and planned interactions; instruction and support for students to maximize successful interactions; knowledge and support (peer training) for typically developing peers to facilitate and encourage meaningful interactions; and training and ongoing support provided to teachers and staff. Training will be developed through the statewide Autism Outreach Project and regional Autism Consulting Cadres including ESD 112.

10. Transition across grade levels or programs will be systematically addressed to prepare all individuals involved in the transition. Written transition plans will include clearly stated responsibilities and timelines for all individuals involved in the transition. A meeting will be conducted, either during the annual conference or at a separate transition planning meeting, to exchange information about effective instructional strategies; needed modifications and adaptations; positive behavior support strategies; methods of communication; and inclusion with typically developing classmates.

TRAINING

11. Training and professional development will be required in order to ensure that all general and special education teachers, paraeducators, principals, speech and language therapists, occupational therapists, psychologists, and all other school employees who have contact with children with autism are adequately prepared to make knowledgeable and appropriate decisions to facilitate delivery of a free appropriate public education.

12. All teachers working with students on the autism spectrum will have specialized training concerning best practices for children with autism spectrum disorders, including understanding of the core deficits of autism; competency in program development; classroom-based approaches to communication and social development; functional behavior assessment; educational and behavioral intervention through positive behavior support plans; data collection; and staff management skills.

13. Administration will support and encourage all personnel working with students with autism spectrum disorders to receive continuing and ongoing education at autism specific workshops and trainings.

ASSESSMENT OF PROGRESS

14. Criteria and standards will be developed for schools and districts to use as a guide in development of Individualized Education Plans (IEP) for students with autism spectrum disorders through continuation of the statewide Autism Outreach Project and delivered through Regional Autism Consulting Cadres similar to the already established ESD 112 Regional Autism Consulting Cadre. Implementation will occur across schools and districts.

15. Criteria and standards will be developed to assess the development and implementation of an appropriate comprehensive educational approach within each school district for students with autism spectrum disorders, through the continuation of the statewide Autism Outreach Project and localized autism cadre development through ESD's across the State of Washington.

16. Criteria and standards will be developed for school districts to regularly assess staff effectiveness in program implementation and use of preferred methods in educating children with autism, through the continuation of the statewide Autism Outreach Project and localized autism cadre development through ESD's across the State of Washington.

17. School staff will have ongoing access to a professional consultant in autism, whose services will include site visits, input on program development, feedback on staff effectiveness and student progress, through the continuation of the statewide Autism Outreach Project and localized autism cadre development through ESDs across the State of Washington.

Funding

1. Fund lifespan intervention services (e.g. basic and special education, early intervention services, adult services, vocational services, housing, mental health, residential)
2. Mandate coverage by private insurance and Medicaid (e.g. Katy Beckett—not based on income) for intervention and treatment
3. Fund the regional centers and related training initiatives
4. Increase funding for individual and family supports

1. Improve provider capacity through ideas such as:

    a. Pay incentives for special education teachers specializing in autism (ie. as evidenced by appropriate certification or specialized training in best practice approaches).
    b. Competitive pay for ancillary services specializing in autism (as evidenced by experience and training in best practice approaches) and working within the public education system.
    c. Coverage by private insurance and Medicaid for IBI (intensive early behavior intervention) and other proven models of treatment, minimum of 25hours/week (to include coverage of professional to design and supervise programming, and tutors to implement – for in home or on-site services depending on age and individualized appropriateness for each child).
    d. CPT coding including ICD-9, relevant to treatment and services specific to autism.
    e. CPT coding/insurance coverage for case management services through medical home model.
    f. Tuition relief/Student Loan reimbursement assistance for providers (special ed teachers, ancillary service providers, and physicians) specializing in autism, committing to work in rural areas and those areas of ethic and cultural diversity (i.e. Reservations, Military, etc.).

2. Empower educational system through:

    a. Increased funding for special education earmarked for ASD and in proportion to enrolled students with ASD.
    b. Increased funding for early intervention “Children Birth – Three/ITEIP”
    c. Increased funding for basic education.
    d. Increased funding for OSPI for use in autism training, programming, resource development, and evaluation (money should be specifically for providing - or contracting for provision of: teacher training, ongoing supervision and consultation by “autism professional” , evaluation of school district progress in educating children on the spectrum, development of criteria and standards for assessing progress of students and staff, and development of standardized process and materials for identifying children and coordinating their referral and access to school services.

3. Ensure regional access to services and resources (through the lifespan) through:

    a. State funding for development of regional centers throughout the state where none exist, and funding continued development and expansion of services (towards becoming a regional center) in areas where a coordinated effort to provide services has already been established (ie., UW's Autism Center and EEU, Tacoma Satellite, Northwest Autism Center, Autism Cadre ESD 112, Yakima Children's Village, Autism Outreach Project, etc…) . Note: **required basic components of centers need to be identified** (refer to centers developed in other states – ie., Florida's Care System, as well as local input). Individualized short and long-term plans for development (of each identified site) addressing those components are required to assure consistency of comprehensive services across state.
    b. Autism Waiver for individual and family supports
    c. State funding to support revision of DDD eligibility requirements providing access to services and resources by individuals on the spectrum and access to respite care (requires appropriate modification of current care assessment tool used for determining personal care hours through Medicaid).
    d. (Speaking of which) Medicaid eligibility for coverage per ASD diagnosis unrestricted by family income (ie., Katy Beckett).
    d. Provide employers with incentives to hire people with ASD.

4. Provide Comprehensive Healthcare and Treatment Through:

    a. Dental Care Coverage for general anesthesia in providing routine dental care (as appropriate/needed by individual with ASD). For consultation/training from "autism professionals" in ongoing treatment and care using positive behavioral supports (to improve quality and consistency of dental care).
    b. Mental Health Coverage for services for children on the spectrum and for adults on the spectrum. Will require revision of current MH eligibility requirements and a concurrent revision of training expected of MH providers (to have autism specialty component).
    c. Coverage of MH services provided within the public school system. Should be a regular presence in every district.
    d. Insurance coverage to support CPT coding for biological treatments and pharmacologic treatments, and follow-up.
    e. Different ways to support people through the life span. (clarify with MM)

Comprehensive Health Services and Coverage, including Mental Health, Dental, Health Disparities

1. Medical homes
   a. make sure kids are getting high quality medical/dental services
   b. make sure physicians talk to teachers, parents, etc.
   c. incorporates cultural competencies
2. Insurance
3. Shortage of professionals
4. Consistency
   a. consistent process throughout the state to determine appropriate medical intervention programs for each individual

Address disparities.

Early screening should be included here, too.

Guidebook and insurance options.

Mental health issue: recommend providing counseling for children with ASD (this is not new, however; already included below)

1. COORDINATION OF EDUCATION AND MEDICAL TEAMS: The education system and Medical Providers need to work together in developing an Individualized treatment plan for children with ASD. For example most pediatrician panelists for the ATF said they work with individual children, not school systems per se to implement an individualized treatment plan. Coordinated education and medical care; must be an integral part of the implementation of an Individualized treatment plan.

2. HEALTH CARE AND MEDICATIONS: The health care for individuals with ASD is vital. Unfortunately the use of medications, or overuse of medications such as psychotrophic and anti-psychotic drugs are prevalent in the medical treatment of ASD. Healthcare providers need to recognize when cognitive/behavioral approaches can be used in lieu of medications or as a complement to medications.

NOTE (Ohio Autism Task Force) It is the recommendation of the taskforce that the Ohio Board of Regents encourage colleges and universities to develop curriculum for students preparing to practice in professional fields providing services to individuals with autism and their families.

Individuals with autism and their families interact with many professionals related to services they need throughout their lives. There is a general lack of knowledge and training in many professions regarding working with individuals with autism and their families. The Board of Regents should encourage colleges and universities to develop appropriate curriculum for students wishing to practice in these fields.

3. INSURANCE: There is Healthcare disparities across Washington State for all disabilities, but specifically for ASD. The lack of insurance coverage for treatment of autism along with a Washington State law that permits individual health insurance plans to exclude services for individuals with ASD. Families need to focus on the care of their child and not the stress of finding services.

NOTE: (Ohio Autism Task Force) It is the recommendation of the task force that health insuring corporations and such other insurers as may be applicable in Ohio be prevented from excluding coverage for services provided to individuals with autism.

Many health insurers in Ohio exclude coverage of services for the treatment of autism. The taskforce believes that this exclusion is based on outdated notions of what autism is and whether manifestations of autism can be treated. Other states have moved proactively by prohibiting such exclusions. Some major insuring corporations have changed their policies regarding the exclusion of autism. The state of Ohio can prompt other health insurers to modify their policies by implementing legislation which prohibits this exclusion

4. MENTAL HEALTH/OTHER HEALTH SERVICES: Access to other health services such as dental and mental health services AND Mental health counselors are being lost/cut.. With the high rate of depression for individuals with ASD, many mental health providers and educators do not have the training to treat them. These individuals go without treatment and end up taking their lives. The ATF recognizes the role of the primary care provider as well as specialists in many different disciplines of medical, psychological medicine and allied health professionals. It is recommended by the ATF that Washington State will have trained Medical, psychological and allied health providers in the field of ASD to provide appropriate services to families and individuals with autism spectrum disorders.

NOTE: (Ohio Autism Task Force) It is the recommendation of the taskforce that the Ohio Board of Regents encourage colleges and universities to develop curriculum for students preparing to practice in professional fields providing services to individuals with autism and their families.

Individuals with autism and their families interact with many professionals related to services they need throughout their lives. There is a general lack of knowledge and training in many professions regarding working with individuals with autism and their families. The Board of Regents should encourage colleges and universities to develop appropriate curriculum for students wishing to practice in these fields.

NOTE: (Ohio Autism Task Force) It is the recommendation of the taskforce that the Ohio General Assembly enact mental health parity legislation.

Autism is not a mental health disorder. However, significant portions of individuals with autism have severe behavior problems. Parents of children with autism experience unusual and ongoing stress. Mental health parity legislation will make mental health services more accessible to individuals with autism and their families. Keeping families together and avoiding costly residential or psychiatric treatment are more likely if mental health services are available.

5. EARLY DIAGNOSTIC SERVICES: The availability of prompt services AND Limit waiting times, especially for early intervention services and diagnostic procedures. (See Early Screening, Diagnosis and Referral to Intervention section of this document)

6. CO-MORBIDITY: Currently there are to few resources for addressing co-morbidity AND No standards of care, especially for co-occurring conditions. Medical and Mental Health providers will receive the training and understanding of co-morbid conditions with Autism through training and standards of competency.

7. ASPERGERS: Not enough understanding of Asperger's and children with Asperger's are grossly underserved. (Should this statement be in the Early Screening, Diagnosis and Referral?)

8. SHORTAGE OF PROFESSIONALS: Access to professionals is lacking AND There is a shortage of trained pediatric sub-specialists AND Make a diagnosis early in a child's life AND Include an evaluation of sleep behaviors. (Possible medical school incentives for Developmental Pediatricians?) Need more input.

9. STANDARDS/METHODOLOGIES: Use evidence-based methodologies for diagnosis and treatment AND Use intense, frequent, and direct methodologies AND Professional best practice guidelines have been developed, but they are only the beginning and they are not yet standards for practice, just parameters.

NOTE: (Ohio Task Force) It is the recommendation of the taskforce that Ohio establish a standard practice of autism diagnosis and treatment.

There is enormous variability throughout the state and within the medical community regarding the diagnostic process related to individuals suspected as having autism. Inconsistencies and delays in completing a diagnosis and in receiving the diagnosis lead to a delay in providing services.

10. BETTER TRAINING ON OPTIONS: There are bottlenecks in diagnosis, treatment, and provision of care. Sometimes providers are hesitant to diagnose a problem they feel they can do nothing about. A lack of awareness about treatment options among primary care providers contributes to this. A provisional diagnosis model would permit treatment to begin before a final diagnosis is made.

11. CULTURE AND COMMUNITY ACCESS: Recognize child as part of a family and in context of culture, community and resources; focusing on the family AND Staff have quickly learned that there are many cultural barriers they were not even aware of.

They have faced challenges in getting families to comply and follow through with a treatment plan. Other providers noted that language is a significant barrier. Attaining services related to ASD is difficult for any family, add any other factor such as socioeconomic, cultural, and language barriers and obtaining services becomes even more difficult. The medical home model incorporates cultural competencies AND Medical Home (parallel to regional centers) AND Use a primary care model that is based on the principle of a medical home AND Utilize a care coordinator, preferably a mid-level practitioner trained to handle complex care AND Autism Treatment Network - best practice approach for health professionals;

12. TRANSITIONING CHILDREN TO ADULTHOOD: There is little support for transitioning from pediatric to adult care.

NOTE: (Ohio Autism Task Force) ***Across the Lifespan***

AL-1 It is the recommendation of the taskforce that Ohio develop an Autism Resource Manual which will include regional services available and regional service providers. The manual should be available online, for public distribution, and at public libraries throughout Ohio.

An Autism Resource Manual will provide information regarding medical, social, educational, and other resources available to parents in Ohio. Input received from parents at many of the regional forums clearly indicates a need for parents to have ready access to comprehensive information about services and resources available for their children with autism.

AL-2 It is the recommendation of the taskforce that there be created a statewide standard and protocol for the effective transition of individuals with autism from one service system to another.

There is no coordinated system to guide parents through difficult periods of service transition. Individuals with autism must transition from early intervention services, to a service system operated by local school districts, and to a system which provides services to adults with autism. Many parents testified to the taskforce that these transitions were very difficult to navigate. To address these concerns a statewide standard and protocol for transitioning individuals and their families should be established and promoted.

AL-3 It is the recommendation of the taskforce that the quality and quantity of family support services available in Ohio should be increased. These family driven services will include, but not be limited to home modifications, respite care, advocacy, care giving, transportation, and family training.

Many parents testifying before the taskforce highlighted the financial and emotional strains caused by a lack of adequate support services. The need for support services acknowledges the impact of the disability upon the entire family. Many testified to the

need of respite assistance so that the rest of the family could attend church or activities of other children.

AL-4 It is the recommendation of the taskforce that an Ohio Autism Center provide continuing education to professions and occupations in the State of Ohio in regard to the attributes and characteristics of individuals with autism and to assist in serving individuals with autism. This shall include but not be limited to continuing education for employees of state and local agencies providing services to individuals with autism.

There is a general lack of training opportunities for professionals coming in contact or working with individuals with autism. This has created a significant gap in services. Testimony from parents provided numerous instances in which public agency staff, with whom they were working, simply did not have sufficient knowledge regarding individuals with this disability. There is a wide spectrum of professional or service personnel who periodically come in contact with individuals with autism who need to be aware of the particular characteristics of this population.

AL-5 It is the recommendation of the taskforce that a statewide analysis be performed to determine whether individuals with autism in Ohio are inadequately served with vocational, adult day care, residential and supported living services.

Community awareness of autism, until recently, was not widespread. Accordingly, individuals with autism who use or need particular services may not have been appropriately identified. One indicator of the need for specialized residential care is the reportedly long waiting lists at residential facilities serving individuals with autism (e.g. Bittersweet Farms and Ardmore). A statewide analysis will determine the extent to which these services are being provided in Ohio and whether the particular needs of individuals with autism are being met.

AL-6 It is the recommendation of the taskforce that the Ohio Rehabilitation Services Commission and the Ohio Department of Development promote appropriate employment opportunities for adults with autism.

The Ohio Rehabilitation Services Commission and the Bureau of Vocational Rehabilitation provide assistance to individuals with disabilities, including autism, and help to prepare individuals for employment. The Ohio Rehabilitation Services Commission, partnering with the Ohio Department of Development, should develop a strategy focusing on the unique strengths, skills and needs of individuals with autism in order to maximize employment opportunities.

Community Supports / Family Support / Inclusion / Respite / Understanding of Autism at Community Level

1. Book—similar to Ohio Service Guidelines for Individuals with Autism
2. Respite
3. Wrap-around services (e.g. after school supportive recreation, employment or child care services, weekend and summer support)
4. Family and community outreach to all
   a. ethnicities—use consistent wording for this one throughout the document]
   b. local, regional, family support organizations (P2P/FN/others)
   c. build on existing models
   d. have families tell law enforcement about their kids with ASD

Parent to Parent and Fathers Network identified by 4 of 5 parent panelists as having been an essential support to their family.

1. SUPPORTS FOR FAMILIES: Support for parents/families of children with autism spectrum disorders AND Need to provide sibling support AND Support parents by getting them information on autism and to help them navigate the system.

2. TRAINING AND INFORMATION: Training for child care providers, including autism information and information on what the family needs.

3. COMMUNITY INTERACTION: Safety and independence of growing kids AND Law enforcement interaction with individuals with autism AND Inclusion of individual into society and community.

4. EDUCATIONAL SUPPORT/TRAINING: Improve the capacity of school districts through teacher training and encouraging parents to educate themselves AND Educators need to understand the needs of kids with ASD AND Peer mentoring for kids is needed since there is often a lack of opportunity for social interaction for children with autism spectrum disorders.

5. CULTURAL SUPPORT: Reach out to diverse communities and families.

6. COMMUNITY COORDINATION/SUPPORT: Each local community has to have a coordinator, someone to bring all the pieces together and know the resources in the community. There are not enough trained professionals to cover the need AND Vision setting regarding adopting the philosophy of a neighborhood school and the designation of an autism specialist and participation in an Autism CADRE AND Use person-centered care with focus on family and family preservation AND A large team of professionals who develop an individualized plan.

7. RESPITE: Explore ideas of local respite resources to give families a break; recreation/leisure resources and feeling of support AND Trained Respite Care Providers for parents through respite care funding to be provided to families of children with autism spectrum disorders.

Transition, Employment, Residential Options and Long Term Care

1. Transition
2. Employment
3. Residential options
4. Long-term care

Transition over the lifespan: services are important for all ages.

Notes: some adult panelists indicated that DVR was not a viable option for them; can be a viable option, however, and should be included as a way to improve the system**.)**

Job and career options limited

One panelist noted that it took concentrated work with mental health therapist to develop self esteem after years of being told she was not ok. Others noted that despite their efforts to find meaningful work, they repeatedly fail to find jobs or lose the jobs due to mismatch between their verbal communication disorders and the needs of the job, and this is very demoralizing.

1. Research based standards for effective transition services with necessary resources for training in interventions for individuals of all ages who experience autism. Create a statewide standard and protocol for effective transition of individuals with autism from one service system to another. Transition for individuals with Autism throughout the lifespan should include;
    a. Education
    b. Medical/Dental
    c. Employment/Supported Employment
    d. DDD
    e. DVR
    f. Residential/Assisted Living
    g. Respite/Personal Care
    h. Counselors

    Autism Spectrum Disorder expertise in transition should be present at regional, local and district levels for information on transition through the lifespan. These programs and services will not have waiting lists. Programs for transition will envelop best practice information and supports through the continuation of statewide autism leadership (AOP) and development of local training programs (similar to ESD112 Regional Autism Consulting Cadre, University of Washington Autism Center, Seattle and Tacoma, Washington Initiative for Supported Employment, Aspergers Support Network, Center for Change in Transition, etc.).

2. Transition School to Post School Activities should included a build-able portfolio based on the individual with ASD core deficits;

i. Communication
j. Social/Emotional/Perspective Taking
k. Focus on generalization and maintenance of skills
l. Learning Style
m. Executive Functioning/Organization/Problem Solving/Choice Making
n. Understanding their Autism, self-advocacy, self-determination

Transition activities should include the collaboration and blending of service resources well before the 21st birthday to support the expertise continuity in supporting an individual with Autism Spectrum Disorders; including schools, colleges, vocational programs, employment, supported employment providers, etc.

3. Supported Employment/Day Program service providers will have specialized training in best practice supports and strategies to support individuals with autism spectrum disorders at work and in the community. The providers and staff will have specialized training in the core deficits of autism; providing competency in employment environment structure/development, functional behavioral assessment, social/emotional, communication, educational and behavioral intervention (through positive behavior support plans), data collection, staff management skills, etc.

   Supported Employment/Day Program providers and staff will envelop best practice information and supports through the continuation of local autism support and resources such as; Washington Initiative for Supported Employment Autism Project, Behavior as Communication (Zachary Carr), etc.

4. Washington State University, Colleges and Vocational programs will have research based standards for effective educational accommodations and modifications for an individual with autism who attends post secondary education. Staff for the Office of Disabilities within Washington State Universities, Colleges, and Vocational programs will have training and competency skills with resources and access to training to support the needs of individuals with Autism Spectrums Disorders;
   o. Career development
   p. Self-Disclosure of Autism Spectrum Disorder
   q. Accommodations and modifications for the class, professor, room mate, etc.

   Autism Spectrum Disorder expertise in post-secondary education transition should be present at regional, local and district levels. These programs and services will not have waiting lists. The Office of Disabilities within Washington State University system will envelop best practice information and supports through the continuation of training in best practices supports for individuals with autism through the statewide leadership of the University of Washington Autism Center, Seattle and Tacoma and the Center for Human Development and Disabilities; Center for Change in Transition Services, etc.

5. Research based standards for effective residential services with necessary resources for training in interventions for individuals of all ages who experience autism. Residential options for individuals with Autism Spectrums Disorders will be based on the individuals' needs of support. Such as;
    r. Companion Home based on evaluation and data from Autism Community Services Program.
    s. Assisted Living Services

    Residential service providers will have specialized training in best practice supports and strategies to support individuals with autism spectrum disorders. The providers and staff will have specialized training in the education of the core deficits of autism; providing competency in residential/home/environment development, functional behavioral assessment, social/emotional, communication, educational and behavioral intervention (through positive behavior support plans), data collection, staff management skills, etc.

6. Community Awareness of Autism;
    t. Employers
    u. Recreation/Leisure Activities
    v. Retail Businesses
    w. Faith Based Organizations
    x. Law Enforcement (there is an interactive training already available).

    Autism Awareness should be present at regional, local and district levels for information on Autism Spectrum Disorders. Programs that present Autism Awareness will envelop best practice information and training through the continuation of our statewide Autism Society of Washington, community chapters of ASW, FEAT, NAAR, Northwest Autism Center, U of W Autism Centers (Seattle/Tacoma), etc.

    Give employers incentives to hire people with ASD

Long Term Care

Most children with developmental disabilities including autism live with their families. More than __% of adults with developmental disabilities live with their families.

Most children with developmental disabilities who live out of their family home are placed because of significant behavioral issues. Out of home placement of children may occur because of abuse or neglect issues or children may be voluntarily placed into out of home care if their family is unable to continue to provide the care that they need.

Out of home placement options include ICF/MR (a placement option that may be an entitlement depending on whether the child or adult meets the admission criteria), child foster care, child group care or staffed residential homes for children. All community based out of home placement options for children are licensed through the Division of Licensed Resources (DLR) in the Children's Administration (CA), Department of Social and Health Services (DSHS). Depending on the age of the child, children that present significant behavioral challenges are usually supported in staffed residential settings.

The average daily cost for each out-of-home placement option is

State operated ICF/MR	$_____/day
Child Foster Home	_____/day
Child Group Home	_____/day
Staffed Residential Home	_____/day

Children with autism may present significant care issues to their caregivers. When families ask for out-of home placement, it is usually because they can no longer cope with the severe behavioral challenges their child presents. Sometimes those challenges include dangerous behaviors to parents and/or to other siblings in the family home.

School programs provide some support to families by engaging the child in learning and development activities for 4-6 hours on weekdays. When the child transitions from public school programs as a working age adult, no consistent support is available for the young adult to be employed. Support does exist in the form of personal care support but often the person's issues are behavioral in nature and support to do personal care tasks does not keep her/him engaged in productive activity leaving the person to react behaviorally.

The best place for a child to be is at home. Family homes must be supported to be safe and healthy environments for everyone in them including parents, the child with disabilities and her/his brothers and sisters. An array of supports should be available to families with the expected outcome of a safe and healthy environment.

For those young people with families who are able to continue to support them after s/he transitions from public school, employment supports are necessary to ensure the person continues to be a productive member of her/his community

For those young people that present severe and/or dangerous behavioral challenges to their families out of home placement must be an option. The out-of-home placement should be in the least restrictive setting cost effective option with the proper support.

Recommendations

1. Support to Families

    - Ready availability of respite with access to providers trained to support people with autism. For example, Autism Family Support Services provides a statewide current listing of skilled respite care providers. Providers should be paid according to the specific level of skills that are required to support the individual they are supporting.
    - Wraparound services should be available to families when periodic respite is insufficient to maintain the family unit. Funding should be available for family preservation services that would include education, training, planning, skilled in-home supports, environmental modifications, respite, personal care, needed support to parents and siblings, mental health and behavioral interventions. Professionals such as case managers, teachers, therapists, family resource coordinators should have ready access to such services and families and family advocates should be aware and informed of availability so that they may make requests.

For additional information please see

- ***Permanency Planning for Children with Developmental Disabilities in Pennsylvania: The Lessons of Project STAR***. (Syracuse, NY Research and Training Center on Community Integration, Center on Human Policy, 1992).
- *Maryland Developmental Disabilities Council* (Catriona Johnson)
- *Tamar Heller and Joe Caldwell; Rehabilitation Research and Training Center on Aging with Developmental Disabilities, University of Illinois at Chicago, Chicago, IL; Journal of Policy and Practice in Intellectual Disabilities Volume 2 Number 1 pp 63–65 March 2005*

2. Once the decision is made that out-of-home placement is required, families should have a variety of possible options that are age appropriate and offer skilled support specifically trained to meet the needs of the individual served. There are a variety of possible options for people. Whatever option is chosen, however, must be age-appropriate, provide sufficient support to meet the person's needs, provide the person as much opportunity to be independent as possible, be periodically evaluated, certified, and/or licensed.

Shared parenting options should be available to families of children. Providers should foster and encourage maintenance of family and friends relationships once the person has moved.

A full description of several current available out-of-home placement options may be found in Appendix ____

For additional information please see

- Report Section on Transition/Employment/Residential Options for recommendations
- Build-able Portfolio from Birth through Adult Life.
- *U of W, Center for Human Development and Disabilities-Evaluation, Lyle Romer, Ph.D, DDD; Seltzer, M.M., Krauss, M.W., Hong, J., Orsmond, G.I. (2001). Continuity or discontinuity of family involvement with adults with mental retardation following residential transitions. Mental Retardation, 39, 181-194.*
- Autism Society of America, 2006

Infrastructure

1. Regional centers
2. FRC across the lifespan/ model providing care coordination
3. Support for interagency coordination and collaboration

Recommend using a regional approach.

Through regional centers, more case coordination/management. Could be assigned a coordinator/ Medical Home strategies.

FRC model could be expanded across the life span. Have a **life span** FRC housed in the regional centers?

The need for care coordination will still be there after someone graduates from school.

Tie in the other systems that parents are involved in: DSHS/Schools/etc.

Global

1. **One entity** should be established to look at the whole system; (recommend regional centers are funded and there is an Advisory Board made up of people who are directors of the regional centers (or current ATF) and consumers that monitor program effectiveness)
2. Develop and/or support **7 regional centers** and one of their tasks is to develop regional **multi-tiered levels** of training;
3. **Wrap around services** should be available year round and outside of the school setting;
4. **1-800- one stop number for autism help/information;**
5. Deliver services within a **medical home/** Physicians will be empowered to adopt the Medical Home concept in providing care to children affected with ASD.
6. Care coordinator like FRC across life span
7. Tie in the other systems that families are involved in: not just medical or school, but DSHS, etc.

Educational Systems (move this section to Schools Section number 5)

1. We need educational standards across the state: Right now it is up to each district ;
2. Decisions (educational) are currently made at the local level;
3. Focus on training;
4. Educational staff don't have the baseline knowledge they need to begin training;
5. Have individual ("Autism Specialist") in every school district who can provide consultation and local training and provide money for a support person in each district;
6. Develop support for educators by their district's administration to reduce staff turn-over and poor training;

7. **Multi-cultural, geographic and inclusion requirements:**
Training for all teachers, peer educators, and other affected staff working with children with disabilities specifically related to intentional inclusion techniques;

Incorporate representatives from minority populations into decision-making processes;

Cultural gap exists because service providers do not look at the challenge from the point of view of parents and children

Break down geographic barriers;

County coordination with clear follow through responsibilities and accountability;

Use advocates for families who practice different cultures and speak different languages;

8. **Unions and other organizational systems**
Address the **impact union practices** have on job assignments and inappropriate staff assignments;

Training systems
Provide recognition and incentives to retain experienced staff;
1. School administrators should be trained and informed;
2. Use the k20 system to provide information to all ESDs;
3. Need equitable expertise available across the state;
4. Statewide recommendations should consider work that is already being conducted;
5. 19.Need more special ed teachers, especially those that are bilingual in English and Spanish;
6. Compensate beginning special education teachers for the additional time it takes to become a special education teacher;
7. Implement peer training programs;
8. Emphasize a successful transition to higher education;
9. Employ staff who can identify and make appropriate accommodations at all levels of education;
10. Increase educational opportunities at the university level and create more opportunities for specialists to learn: could generate more trained professionals.
11. We need Developmental Disability medicine added to medical school curriculum.
12. Offer teachers an “inclusive education” degree
13. Legislature has provided increased funding in the past ten years for ‘high demand fields.’ It is still a challenging to get people to go into those fields and to work in public services when the rewards are greater in private practice

Assessing Effectiveness of Programs and Services

1. Data collection (e.g. prevalence, incidence, service provision, cost analysis)
2. Assessment (e.g. Center for Transition and Change)
3. Evaluation
4. Quality management of services

affected individuals receiving services

providers (whether individual or system)

funding (cost benefit analysis)

Based on its work over the past few months, the Autism Task Force recommends a number of additional strategies/programs/interventions to address the needs of Washington citizens with autism. These recommended additional interventions are data-based and proved effective in improving outcomes.

At the same time that the Task Force makes these recommendations, it is also imperative that a quality assurance process be attached to any new strategies implemented as well as to current efforts in the field. This recommendation is made for two reasons. First, the Task Force would like to ensure quality of implementation for any program and would like to begin building evidence-based practice in providing services to people with autism

The Task Force recommends a Quality Assurance process be built into any program or service and that the quality assurance process show capacity to assess the effectiveness of the program/service.

The quality assurance process should have the following characteristics:

1. Family Friendly including being able to demonstrate that the program/service
    - listens to parents/family
    - has a complaint policy that includes
        - how to make a complaint
        - who will follow up on complaint
        - timeframes for response to complaint
        - definition of when complaint is determined to have been addressed
        - appeal process
    - solicits periodic feedback from other people involved with the person
    - encourages family participation, support and involvement

2. Describe purpose of the program including proposed goals and objectives and how the program will assess achievement

- Describe measures/data points designed to determine program/service success
- Describe how measures/data points will be taken/collected
- Some examples include reduction in symptoms or medication, increased participation in typical activities, improvements in communication, obtaining and keeping a job, satisfaction with services, observable changes in behavior or responses, improvement in general or specific health conditions including oral health, improvements in sleep time

3. Demonstrates that the people it hires have the skills, expertise and experience to implement achieve the program/service purpose/mission

4. Demonstrates it has a training curriculum that ensures the people responsible to achieve its purpose, goals and objectives is current with current competent, qualified or licensed practice
    - Some examples include teachers, social workers, case managers, direct support staff are knowledgeable about autism; Individual Family Service or Education or Support (IFSP, IEP, ISP) demonstrate knowledge of autism; IFSPs/IEPs/ISPs document appropriate goals and objectives that are consistent with the individual's needs and measured against individual goals

5. Regularly monitors its achievement of its program purpose, goals and objects and uses its self-monitoring to change, modify and/or improve practice.